



**Karolinska
Institutet**

Institutionen för Neurobiologi, Vårdvetenskap och Samhälle

Subjective experiences of dignity within mental health care

AKADEMISK AVHANDLING

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ABSTRACT

Background: The importance of respecting people's inherent dignity was put on the agenda during the last century with the United Nations Universal Declaration of Human Rights. From a caring science perspective, the importance of meeting people with respect and taking care of their absolute dignity is also emphasized. Despite all this, patients at psychiatric hospitals still experience suffering and reduced dignity.

Aim: The overall aim for this research was to explore patients', relatives' and staff members' views concerning patient dignity at mental health hospitals. In paper I. the aim was to gain a deeper understanding of how the staff in a psychiatric hospital perceive dignity in their encounters with patients and their understanding of what influences a patient's experience of dignity. In paper II, the aim was to gain a deeper understanding of the subjective experiences of patients in a psychiatric hospital with respect to dignity. The purpose in paper III was to reveal relatives' opinions regarding what is important for ensuring the preservation of a patient's dignity when they are admitted to a psychiatric hospital. In paper IV, the focus is on common experiences of patients and relatives in terms of how the dignity of the patient was taken care of when they were admitted to psychiatric hospitals.

Method: Two different methodological approaches have been applied. In studies 1, 2 and 3, a Q methodological approach was applied. Based on a Q sort (a collection of statements) developed from qualitative interviews, staff members, patients and relatives were instructed in sorting 51 statements. Patients were asked to order the statements in a grid from those they most agreed with to those they most disagreed with. Relatives and staff were asked to rank the statements based on what they felt was relevant for the patients' experience of dignity. Post-interviews were performed, with all the participants immediately after they had sorted the statements. The analysis of data was done by performing by person factor analysis for all the patient-, relatives- and staff studies (papers I- III). In study 4, a Phenomenological hermeneutics method for researching lived experience guided the analysis of qualitative interviews conducted with patients and relatives.

Results: In *study 1* (paper I), 25 staff members participated and two different viewpoints emerged. Viewpoint 1 was given the name: 'Patient Focused Staff', while viewpoint 2 was called, 'Challenges for Staff'. In *study 2* (paper II), 15 patients participated, and four different viewpoints emerged. Viewpoint 1 was described as, 'Being met as equal human beings'. Viewpoint 2 was named, 'Experience of dignity despite suffering'. Viewpoint 3 was interpreted as, 'Suffering due to feeling inferior'. Viewpoint 4 was described as, 'Suffering and fighting for one's own dignity'. *Study 3* (paper III), was about relatives' viewpoints. Thirteen relatives participated and four different viewpoints were identified. Viewpoint 1 was named 'Value based', viewpoint 2 was about 'Expectations', viewpoint 3 was given the name 'Asymmetric', while viewpoint 4 was described as 'Nuanced'. In *Study 4* (paper IV), one main theme and four sub-themes were revealed. The main theme was described as, 'The significance of small things for the experience of dignity', while the sub-themes were described as, 'To be conscious of small things', 'Being conscious of what one says', 'Being met' and 'To be aware of personal chemistry'.

Conclusion: Within each group of patients, relatives and caregivers, differences but also consensuses were found. Also similarities across the studies were found. The staff's way of meeting patients and relatives has a direct influence on the patient's experience of dignity. In encounters where the patient's- and relatives' experience of being met by staff represents values such as equality and respect for humans' uniqueness, they experience that the patient's dignity was being taken care of. All staff members also emphasize this, with some staff also focusing on challenges related to this. Some patients and relatives communicate that there still is an imbalance in their relationship with carers, which is something that increases a patient's suffering. Other patients and relatives sometimes found it necessary for the staff to take control over the patient's situation. For caregivers, being aware of their responsibility towards a patient's suffering opens up an opportunity for a compassionate self in an authentic encounter with patients. As discussed in paper IV, how staff members behave, in addition to putting a focus on small things in each unique encounter with patients in a dignity promoting- or dignity inhibitory way, reveals to what degree the staff are aware of their ethos, as well as to what degree both the individual staff members and the caring culture can be experienced as being ethical or not ethical.

Key words: Dignity, suffering, psychiatric hospital, patient, relatives, staff members
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